Innovative Approaches for Eliminating Mother-to-Child Transmission of HIV

Community Mentor Mothers
Empowering Clients Through Peer Support A Spotlight on Uganda
Optimizing HIV Treatment Access for Pregnant and Breastfeeding Women (OHTA), a UNICEF-supported initiative with funding from the Governments of Norway and Sweden, aimed to accelerate access to Option B+ for the elimination of mother-to-child transmission in Côte d’Ivoire, the Democratic Republic of the Congo, Malawi, and Uganda. Option B+ is an approach recommended by the World Health Organization in which all pregnant and breastfeeding women living with HIV are offered treatment with antiretrovirals for life regardless of their CD4 count.1

The OHTA Initiative’s primary focus was to strengthen the capacity of the primary health care system to deliver lifelong HIV treatment to pregnant and breastfeeding women; create demand for programmes aimed at preventing mother-to-child transmission (PMTCT), increasing uptake and timely utilization of PMTCT programmes by women, and retaining women in care; and strengthen monitoring and evaluation for decision making to improve service delivery.2 The OHTA Initiative was implemented between 2012 and 2017 through in-country implementing partners.

"If I get a client, I really put myself in their shoes because I know what it means [to live with HIV].... it is hard, but I will tell her I'm ready to support you through all this, I'll support you even if it means you need me to come to your home to help you disclose because I know how hard it is. It took me two years [to disclose my status]. How can I tell a young mother of 16 years who has tested positive that you can tell your partner the next day? I just have to assure her, I'm there to support you. I'll support you through all this.”

— m2m staff member, Uganda

Uganda has made crucial progress in recent years in scaling up ART and PMTCT. Since 2010, new HIV infections and AIDS-related deaths have decreased by 47 per cent and 56 per cent, respectively,3 and the country has achieved an unprecedented 82 per cent decline in the number of children acquiring HIV.3 Despite these accomplishments, in 2016, there were an estimated 52,000 new HIV infections among the total population and 5,800 AIDS-related deaths among children 0 to 14 years old.4 Additionally, although more than 95 per cent of pregnant women living with HIV were receiving ART, more than 4,600 children were newly infected with HIV in 2016, with only 30 per cent of HIV-exposed infants tested before two months of age.3

Better service delivery and improved uptake, adherence, and retention in care are essential to the achievement of universal access to lifelong antiretroviral therapy (ART) for people living with HIV, and innovative approaches are often required. Individual client support, such as peer support and counselling from a Mentor Mother who has been through PMTCT programmes herself, has been identified as a promising practice to support lifelong ART in Uganda.5 The Mentor Mother approach, which has been implemented in countries all over the world, has been found to improve ART retention, early infant diagnosis, infant ART initiation, the number of antenatal care (ANC) visits, and disclosure of HIV status.6,7,8

What Are Community Mentor Mothers?

Mentor Mothers provide services in health facilities, such as one-on-one support to women, referrals to relevant maternal and child health services, and follow-up services. This
approach is well established and documented, and has been implemented in many countries, including Uganda.6,7,8

In an effort to strengthen community-facility linkages and prevent loss to follow-up of women living with HIV, the OHTA Initiative supported and funded the initiation of a Community Mentor Mother (CMM) programme – the first of its kind in Uganda. The programme was in collaboration with mothers2mothers (m2m) and the Government of Uganda to implement, test, and document a CMM programme in six districts – Bugiri, Iganga, Kaliro, Kamuli, Mayuge, and Namayingo – serving 12 communities and 20 health facilities. Lessons learned from the implementation of CMMs under the OHTA Initiative have been used by the country to inform current PMTCT programming but can also be used globally to inform future PMTCT programming and global efforts to achieve universal access to lifelong ART.

CMMs provided similar services as facility-based Mentor Mothers, but worked primarily in the communities in which they lived to reach women living with HIV and their families. Village Health Team (VHT) members conducted community mapping and provided CMMs with the names and location of mothers for follow-up services and/or ANC. Home visits were provided for general reproductive, maternal, newborn, and child health in order to protect the HIV status of the mother and minimize stigma. During home visits, CMMs discussed with families the importance of early ANC, HIV testing, PMTCT, tuberculosis pre-screening, nutrition and immunization, and provided personalized psychosocial peer support to support and encourage disclosure of HIV status, ART adherence, and attendance at scheduled ANC visits. CMMs conducted home visits to newly pregnant mothers, regardless of their HIV status, to promote early ANC and HIV testing and counselling, and to provide referrals to the health facility. If the woman or her child tested positive for HIV, a CMM followed up two weeks later to discuss treatment adherence, provide additional education and support, and connect them to community support networks. CMMs also conducted home visits to women who missed appointments at the facility. Women were identified for follow-up at the facility level by VHT members and facility Mentor Mothers.

In addition to home visits, CMMs also delivered general health education talks in the community during community events that focused on maternal, newborn and child health, and PMTCT. To support their ability to conduct home visits and provide community support, CMMs received a bicycle or, in urban areas, were reimbursed for public transportation costs. They also received mobile phone credits to make reminder phone calls to women.

"They [women living with HIV] like interacting with them [CMMs] more [than health workers]. They are more close to the mothers. Actually they know the mothers better than the health workers themselves. They are like friends, like family ... That great bond between the Mentor Mothers and the positive women."

— Former Mentor Mother, m2m staff member, Uganda

Recruitment and Motivation of CMMs
m2m worked with the Ministry of Health (MOH) and district health offices – for district and facility-level support – to assess which facilities and communities qualified for a CMM according to the prevalence of HIV among women seeking ANC at the facility. If the community qualified for a CMM, an advertisement for the position was posted in the facility and around the community. Applicants were interviewed and must have met the requirements for the position, which included being a woman living with HIV, having disclosed her status to others, and being willing to discuss with others her experience living with HIV. They also needed to be able to read, write, and speak in the local language.

Once in the programme, CMMs served for one to two years, to allow other women living with HIV the opportunity to be mentors. Mentor Mothers who applied were often motivated by an interest to help other women living with HIV in their community, having a job, earning a modest salary, and having the opportunity to gain additional skills and training. Most mothers who applied were also motivated by the respect that a CMM held within the community.

Training and Supervision of CMMs
All new CMMs participated in a two-week pre-service training conducted by m2m, which provided comprehensive in-depth information on basic medical information about HIV and AIDS – including routes of transmission, prevention, testing, nutrition, breastfeeding, and family planning – and the importance of ART adherence, facility deliveries, and disclosure. The training also covered interpersonal skills development, communication,
confidentiality, and community engagement as well as the steps for conducting a home visit. Additionally, all CMMs received a one-week in-service training biannually and ad-hoc trainings on new guidelines as necessary. Before initiating home visits and education sessions at the community level, all CMMs worked at the health facility for a two-week period to learn from health workers and facility Mentor Mothers and to gain understanding of the importance of community-facility linkages. The formal Mentor Mother training curriculum for Uganda was modified by m2m to create a CMM-specific training to align with MOH messaging.

“Families and communities that have been reached by [CMMs] reported there is an impact for the Mentor Mothers to allow them to come out of their closet and communicate their status to both their families but also to their communities, and be able to live with it [HIV] in a positive and dignified manner.”

— m2m staff member, Uganda

Some Mentor Mothers also served as site coordinators and were responsible for overseeing CMMs, conducting monthly data review meetings, and ensuring quality reporting and programme oversight. Site coordinators also occasionally supervised CMMs in the community to observe education sessions and provide on-the job supervision. Site coordinators, CMMs, facility Mentor Mothers, and midwives met weekly for facility review meetings to ensure community-facility linkages. Project managers and MOH officials also supervised Mentor Mothers throughout the programme to ensure Mentor Mothers addressed concerns and provided accurate information during health sessions and that they knew how to accurately complete forms, thus ensuring the delivery of quality services and reporting.

Generally, one CMM was employed per parish, each supporting seven villages. Additionally, one site coordinator was employed per subcounty, supervising approximately seven CMMs. Between 2014 and 2017, m2m employed a total of 90 CMMs and 12 site coordinators in 12 subcounties.

Outcomes of the Community Mentor Mother Programme

Since 2016, CMMs in Uganda have provided education to more than 19,000 couples through home visits. Additionally throughout the course of the programme, CMMs:

- Reduced stigma associated with living with HIV through community sensitization and education
- Strengthened community-facility linkages by referring families to care and following up with women who discontinued care
- Improved women’s comfort with seeking care through personalized support and education
- Provided confidential peer support and individual health information to women living with HIV
- Nurtured supportive community environments and support systems for women and children living with HIV
- Strengthened male engagement through home visits and education
- Were empowered through trainings in health education and communication strategies

Essential Components and Factors for Success

Several factors were identified as essential to the success of the Mentor Mother programme under the OHTA Initiative including:

Individual:
- CMM expectations, roles, and responsibilities were clearly defined and understood
- CMMs were motivated by empowering other women to prevent mother-to-child transmission, gaining additional skills, and receiving community recognition
- CMMs were from the communities in which they work and were seen as relatable peers

Interpersonal:
- Peers provided individualized client support to identify and address adherence challenges
- One-on-one psychosocial support provided women with a private setting to ask questions
- CMMs ensured confidentiality and built trust with the client

Community:
- CMMs supported pregnant women to adhere to treatment
through home visits
- CMMs provided holistic health education to families during home visits
- CMMs promoted male engagement by including men in health education sessions during house visits
- Home visits, community support groups, and education sessions strengthened community-facility linkages
- Existing structures and networks, such as VHTs, helped CMMs identify women for services

Facility:
- Standardized reporting tools ensured client tracing and identification
- Clear supervision structures ensured CMMs receive support
- Strong monitoring and evaluation mechanisms assessed progress and track clients

Structural:
- Provision of bicycles to CMMs ensured a means of transportation to conduct home visits
- Provision of modest salaries helped motivate CMMs
- Tailored training better prepared CMMs for their specific roles and responsibilities

Considerations for Scale-Up and Sustainability

Through the OHTA Initiative, CMMs in Uganda strengthened community-facility linkages and played a critical role in identifying women for early ANC and HIV testing, and preventing loss to follow-up by providing peer and psychosocial support to women living with HIV in their communities. Several factors should be weighed when considering replicating or scaling up this programme nationally or in other settings.

• **Financing:** Consistent funding should be available to support a modest salary for CMMs, supervision of CMMs, and resources for reporting such as stationary. Funding is also required for the extensive pre-service and in-service training, one of the key factors for the quality and success of CMMs. Finally, funding is needed to provide and maintain a bicycle for each CMM, and provide CMMs with mobile phone credits for reminder phone calls. When feasible, public-private partnerships with local phone companies could be considered to support the provision of mobile phone minutes and minimize programme costs.

• **Health Workforce:** Working through existing community structures and networks, such as pre-formed VHTs, can increase credibility and sustainability of the programme. A peer-to-peer model among CMMs themselves may also be considered to ensure CMMs receive support and maintain participation. Additionally, job responsibilities of CMMs, VHTs, community health workers, and facility-based staff should be clearly defined and understood in order to limit task shifting to CMMs that could negatively affect their workload and reduce their ability to provide personalized support and care to clients.

• **Supply Chain:** Consistent stock of critical ART medications and testing kits are needed to ensure clients return to care and receive the services they need when they are referred to a facility by a CMM.

• **Location:** Geographical differences between urban and rural areas should be considered in every context. For example, distance to the health facility, family relocation due to work, and client tracing in urban areas where people move frequently and do not know one another can cause challenges to adherence and follow-up. Additionally, scaling up the programme to urban areas where additional barriers may be present, such as a lack of community feeling and less attachment to neighbours, requires further consideration and adaptation. Implementation of family support groups could be an alternative in areas where home visits are not feasible.

References


Methodology for Documenting Mentor Mothers as a Promising Practice

The Johns Hopkins Center for Communication Programs (CCP) supported the documentation of this promising practice. Information and data were collected through a desk review of existing OHTA Initiative documents, including annual reports, implementing partner reports, and presentations. Site visits by CCP and project staff were also conducted, including interviews and focus group discussions among implementing organizations, Ministries of Health, and programme implementers.

For more information about the OHTA Initiative, visit http://childrenandaids.org/optimizing%20HIV%20treatment%20access.

For more information about UNICEF’s HIV and AIDS programme, visit childrenandaids.org.

This paper is published by the HIV and AIDS Section, United Nations Children’s Fund, 3 United Nations Plaza, New York, NY 10017, USA.


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